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ABSTRACT

The paper presents case studies of two severely and profoundly retarded adults at an activity center in which training is aimed at motor development and its impact on social adjustment as well as independent functioning. In each instance, an individualized program and home component were designed. Appended are Ss' evaluation data on charts of communication, self help, occupation, and socialization development. (CL)

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MOTOR TRAINING OF SEVERELY RETARDED PERSONS FOR PREPARATION FOR INDEPENDENT LIVING: CASE STUDIES[1]

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Abstract

The concept of independent living, which has been evolving for a number of years, implies achievement at the highest level possible, without an immediate vocational goal. The focus is on improving the quality of life of severely impaired persons. This paper describes two typical case studies of severely and profoundly retarded clients, undergoing training at an activity center. The uniqueness of the training effort is the blending of diagnosis, and program planning and evaluation. The generalized approach to program planning which has contributed to significant progress in these cases relate to motor training, application of operant procedures, and promoting transactional relationships between the individuals and the societal context. These program elements are moderated by and adapted to the specific needs of the individuals. The procedures reported in the case studies suggest methodologies for emulation in similar programs.

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In this paper the concept of independent living and the theme of adapted physical education as they apply to severely retarded persons are discussed briefly. A diversified program of developmental activities adapted to the needs and interests of these individuals leads to many levels of functional independence. The Independent Living Rehabilitation (ILR) program provides a linkage with the home activities, so that the training received at the activity center could continue at home, and thus improve the ability of severely retarded individuals to live independently and function normally within their family and community.

The purpose of the study is to present a prototype of ILR services, which encompass diagnostic, interventional, and evaluative techniques derived from a single clinico-educational instrument. The systematic approach in this program is exemplified by two case studies representing severe and profound levels of mental retardation.

Independent Living Rehabilitation

With the passage of the 1978 amendments to the Rehabilitation Act of 1973, the Independent Living Rehabilitation has become a reality. ILR services are designed to "meet the current and future needs of individuals whose disabilities are so severe that they do not presently have the potential for employment but may benefit from Vocational Rehabilitation Services which will enable them to live and function independently" (Institute on Rehabilitation Issues, 1978, p. i). This concept of independent living is interpreted as follows by Commissioner Robert R. Humphreys (1978) of Rehabilitation Services Administration: "... services to disabled people without an immediate vocational goal, and services over and above those traditionally provided through vocational rehabilitation to improve the quality of life." Concisely and tersely, it implies achievement at the highest level possible. This guiding principle determines the

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nature of services for individual clients provided in the nonresidential adult activity center, where the study was conducted. The array of services include major life activities, social-recreational services, and occupational skills wherever feasible.

Adapted Physical Education

Because of their limited intellectual abilities, the programs for mentally retarded persons focus on psychomotor functions which have vocational implications. Motor proficiency has also implications for personal-social adjustment, and sensorimotor development. The need for physical therapy for the retarded is well documented in Kephart's (1960) "motor learning," Barsch's (1967) "movigenics," Asher's (1969) "total physical response technique," and Wolfensberger's (1972, p. 130) "movement oriented curriculum." The research literature on mental retardation tends to point out that "the more severe the retardation the more significant is the physical objective" (Arnheim, Auxter, & Crowe, 1973, p. 259). Because of these considerations, physical education is adapted to the goals and objectives of mentally retarded training programs. Adapted physical education is defined as "... a diversified program of developmental activities, games, sports, rhythms, suited to the interest, capacities, and limitations of students with disabilities who may not safely or successfully engage in unrestricted participation in the vigorous activities of the general /physical/ education program" (U.S. Office of Education, 1950). The motor activities, as designed, are highly individualized specially in the case of severely retarded, multiply disabled individuals. The activities are integrated into the total training program, and monitored by professionals. The training involves gross motor activities classified as basic skills, as also fine motor skills such as eye hand coordination, finger dexterity, etc.

Method

This investigation was based on a case study approach. It was conducted in an adult activity center of the Baltimore Association for Retarded Citizens. Two subjects who typified mental retardation at the severe and profound levels were selected for the purpose. These subjects were ideal cases for the ILR program. The data were collected from their case records, from the interviews with the respective Client Program Coordinators (CPC's) and the Center Supervisor, and from watching the subjects in their activity oriented programs.

Assessment/Teaching Tool

For all intents and purposes, the independent living concept juxtaposes the operational philosophy of the education/training of the mentally handicapped person, as espoused by Gunzburg (1976) in his PAC (Progress Assessment Chart) approach. PAC performances suggest improvements to be produced. In this context, the PAC model seems well-suited as an assessment/teaching tool in independent living programs.

The PAC serves as a developmental index in "personalization" and "socialization." It is a systematic observation technique, which provides a visual check of functioning and progress in the four main areas of social development, namely, Self-Help, Communication, Socialization and Occupation, and in various aspects of personal development. A number of PAC forms have been designed for mentally retarded children, adolescents, and adults of all ages and intelligence levels. These forms are used as appropriate to the level of functioning, and age is not regarded as the decisive factor.

Statements referring to relevant skills and behavior are listed in the inventories of the PAC, and achievements and deficiencies are thus pinpointed with some accuracy. The social diagrams provide not only visual records of present functioning but relate successes and failures to efficiency levels and

degrees of social acceptability. They should be compared with the diagrams of previous assessments, and such comparison would indicate whether remedial education and training have been effective. The assessment on the PAC represents the first vital step toward an individualized program, which is based on the diagnoses of specific weaknesses. Since the PAC identifies underdeveloped abilities in need of special attention, the assessment provides also an itemized teaching program for further action. The regular use of the PAC makes it possible to monitor the progress of social rehabilitation programs.

While the PAC procedure provides a "qualitative picture" of social functioning and dysfunctioning, a "quantitative evaluation" of the general situation is obtained from the PEI (Progress Evaluation Index). The "average attainment levels" of various age groups are indicated in the PEI diagram, from which the "skill values" are derived for each of the areas of social development. The SCI (Social Competence Index) for each area is obtained by multiplying the skill values by the number of skills acquired in that area. Besides the SCI's of the specific areas, the general SCI may also be obtained from the total number of skills mastered. "This procedure, unlike the usual testing, does not compare the mentally handicapped individual with the average achievement level of the general population (the 'normal' level) but compares the social development of a particular mentally handicapped child or adult with the average social functioning of a group of mentally handicapped persons" (Gunzburg, 1976, Vol. 1, p. 22).

Individual Program Plan

IPP includes a detailed list of strengths/needs in different areas: Self-Care, Home Skills, Survival Skills/Cognition, Structured/Unstructured Leisure, Socialization/Communication, Mobility, Contract/Pre-Vocational, and Other. The list is completed by reference to the PAC inventory, which serves

as a screening device for identification of the skills and thus provides the base line data for program planning. The strengths/needs list is checked in the context of medical and psychological reports, and further referral services are initiated if necessary. The goals and program plans are formulated from the needs identified, and the training agreement is completed thereafter.

Case Studies

Subject A

The subject was an institutionalized black male, who had to be commuted to the activity center everyday for participation in the program developed for him. He was 22 years of age, 49 inches in height, and 62 lbs. in weight. The diagnosis was profound level of mental retardation, with etiologies of Down's Syndrome and microcephaly. These conditions accounted for extreme deficits in physical and motor development. The subject was non-ambulatory, and without any speech. He also exhibited spasticity. Besides, he had cataract in the left eye.

The psychological evaluation conducted in January 1978 (at age 21) reported that, based on observational techniques, the subject's development was at the MA level of 0-4 years as measured by the Slosson Intelligence Test. An IQ substantially below 20 - too low to provide any validly discriminating information - was derived from this estimate of his developmental level. The subject had virtually no control over gross motor movements, and was, therefore, strapped into wheelchair. His physical development had been extremely thwarted, and, consequently, his body appeared small and fragile. He was minimally aware of his environment, and his overt behaviors reflected little responsiveness to stimuli around him. Throughout the evaluation, the subject engaged in self-stimulatory and self-abusive behaviors including banging his head and pinching layers of skin on his chest. He wore a protective helmet to guard against cerebral damage.

The subject had no expressive and receptive language skills. His only verbalizations were growling and grunting sounds. The subject's visual perception was impeded by strabismus, and extreme cognitive deficiency. Neither his gross nor his fine motor skills developed beyond the levels observed during early infancy. He was unable to stand or sit without support. His only abilities were associated with extremely simplistic motoric expression and environmental attentiveness, e.g., increasing activity at sounds or objects, grasping an object which has been placed in his hand, and turning head toward a noise. All other skills pertaining to cognition, language, perception, and expression were immeasurably deficient.

The recommendations for program planning were: (1) The subject should continue in the activity center placement; (2) Although the subject may require institutional care in the future, attempts should be directed to increasing his social awareness, gross motor movements, and feeding skills; (3) The subject should be referred to the behavioral consultant who could develop and implement a program intended to decrease self-abusive behaviors. It was further suggested that, because of his low level of functioning, the strategies would necessitate the use of primary reinforcers and the introduction of behaviors which were incompatible with self-abuse.

Because of the severity of his handicapping conditions, the P (Primary)-PAC was used at this stage (January 1978) to identify the practical issues related to the training of the subject. This inventory "refers to the early development of a very young normal child and is suitable for mentally handicapped children to approximately 7 years of age and sometimes older" (Gunzburg, 1976, Vol. 1, p. 15). The P-PAC findings are depicted in Figure 1.

Insert Figure 1 about here

Based on this assessment, it was decided that the subject should continue working in the areas which had been identified earlier (June 1977), namely, (1) Feeding - to scoop food from the scoop dish upon a given command; and (2) Toileting - to be taken to the toilet upon arriving at the activity center, after lunch, and after rest period - toilet check every half-hour as well. A program was also set up in occupational therapy to increase functioning in the following areas: (1) Oral motor skills - to administer the pre-feeding stimulation program daily, and also to assist through the feeding process in using a built-up handle spoon and a scoop dish; (2) Reach and grasp - a variety of textures are rubbed on the subject's hands and arms, and he is encouraged to hold many objects to stimulate grasp; (3) Body awareness - gross motor activities, such as rolling on an incline, swinging from a tire, activities with a roll, kneeling and standing experience (The prone board was used for standing experience).

The following long range goals were formulated based on the activities mentioned above:

1. Self-Help - will be able to eat with a spoon without assistance;
2. Social - will make eye contact for 10 secs., in order to work on any given task (e.g., placing pegs on pegboard, stacking blocks);
3. Fine Motor - will hold on to an object for 15 secs., long enough to decrease his head banging.

On the basis of the principles of task analysis, the goals were broken down to component acts for implementation. The results of this training effort were reassessed by means of the P-PAC after one year in February, 1979 (at age 22), and are presented in Figure 2.

Insert Figure 2 about here

A comparison of the diagrams in Figures 1 and 2 shows the gain in skills in the four areas of social development, which are reflected in the column diagrams in Figure 3.

Insert Figure 3 about here

As the subject was 22 years old, his performance was compared with the 7-year old norm, that is, the oldest group on the P(Primary)-PEI diagram, and the SCI's were obtained accordingly. These SCI's, recorded in Table 1, showed appreciable improvement - a total of 9 skills - over the past year. In spite of this gain, the subject was not only underfunctioning considerably when compared with the average achievements of the 7-year old norm of mentally handicapped children, his level of performance was even lower than that of 2-year old children in the areas of Self-Help, Socialization, and Occupation. Only in Communication, he was functioning at the level of 3-year old children. It is not difficult to imagine why this young man was performing so poorly. Additional handicaps, combined with lack of opportunity and experience due to long time institutionalization, were the main cause for his inordinate backwardness.

Insert Table 1 about here

Edible reinforcements, such as apple sauce, and pudding, were generally used for correct performance of program activities. The subject was currently involved in a regular physical development program which lasted for one hour

each morning. The program was geared to: (1) Movement of arms and legs; (2) Walking a few steps with a walker; (3) Use of mirrors to stimulate psychomotor functions. The staff at the activity center and at the residential institution also made a conjoint effort to assure practice and continuity of the living skills learnt by the subject at the center. For this purpose, team conferences were periodically held at the institution in which the CPC and the Center Supervisor were invited to participate and informative records exchanged.

Subject B

This subject was a 25-year old white female, 5 ft. 2 in. tall and weighing 125 lbs. She was diagnosed as severely retarded (IQ 33 on Slosson Intelligence Test), and her gait was greatly affected by spastic cerebral palsy. She had corrective surgery in 1965, 1967, 1968, and 1969, and also had hysterectomy and appendectomy in 1970. She was restricted from any strenuous activity.

The subject was born three months prematurely. She did not stand up until she was 1-1/2 years old, and she also walked very late. She was inadequate in self-care skills, and she knew very little about getting around by herself by walking or by bus. She lived with her mother, and there were no other members in the family. Her mother was rather overprotective.

The subject attended special school for mentally retarded children. She responded well both to her peers and teachers. Her speech was not much affected. She could recognize words, and write her name. She was good in the area of arts and crafts. Because of her difficulty in walking, she needed use of canes to move about.

The results of the S/PAC 2 inventory administered to the subject in June, 1978 (at age 24) were used to derive the baseline data for purposes of this investigation. The social diagram is presented in Figure 4.

Insert Figure 4 about here

The S/PAC 2 is specially designed for the severely mentally handicapped adult. A new technique has been introduced in this instrument by differentiating in the diagram between "prompted" and "unprompted" activities. The "prompt area" represents the first five skills in each subsection, whereas the "unprompted area" accounts for the second five skills (each preceded by a number beginning with X). The latter area "refers to skills which are carried out on the mentally handicapped's own initiative and volition and which, therefore, include decision and choice" (Gunzburg, 1976, Vol. 2, p. 67).

The S/PAC 2 also provides for the personal assessment, which is primarily intended for determining the "tolerance level" of the open community. "On the rating scale 1 to 5, point 1 represents the extreme of behaviour unacceptable in the community and point 5, the type of behaviour which does not interfere with the general standards or requirements of the open community" (Gunzburg, 1976, Vol. 2, p. 97). The results of the personal assessment (at age 24) are depicted in the diagram in Figure 5.

Insert Figure 5 about here

Based on the above social and personal assessments, the strengths/needs list was developed from which priority goals were derived. These goals were:

1. The subject would comprehend and follow simple sewing skills (such as threading needle, choosing thread, basic stitch);

2. She would match size and color of articles used in developmental skills (such as sorting papers, gluing items);

3. She would manipulate a stapler independently;

4. She would demonstrate the understanding of time verbally, stating the correct time as shown on watch or clock;

5. She would comprehend and follow simple directions independently;

6. She would recognize common survival words, and know their meanings;

7. She would develop self-confidence when walking around the activity center. (She was currently using canes; was holding on to others, or walls, furniture, etc.);

8. She would comb and brush her hair independently.

The staff at the activity center were all along trying to involve the subject's mother in the program activities and to collaborate with her, so that the subject might function properly in the realistic situations of the home environment. According to the mother's report at the time of the social and personal assessments, the subject could perform the following chores at home:

1. Folded hand towels and washed clothes;

2. Pasted labels on boxes;

3. Sorted by size and by color;

4. Stacked her dishes, while sitting at the table;

5. Could wash off tables;

6. Put food from plastic containers into pans or dishes (nothing from cans with rough edge);

7. Could dry silverware;

8. Could fold paper napkins;

9. Other sit-down jobs, or one-hand jobs;

10. Also played jig-saw-puzzles, as a pastime.

The effectiveness of the social education and training for the subject was judged after one year in June 1979 (at age 25), by means of the S/PAC 2. All through the program, verbal praise and social reinforcements were used to strengthen desirable operant behaviors. The social and personal assessment diagrams, exhibiting the findings of the reassessment, are presented in Figures 6 and 7 respectively.

Insert Figure 6 about here

Insert Figure 7 about here

A comparison of the social diagrams in Figures 4 and 6 shows that, over a one-year period, the subject gained only one skill in Communication in the "prompt area," and regressed by one skill in Socialization in the "unprompted area." Similarly, an analysis of the personal assessment diagrams in Figures 5 and 7 reveals that the subject improved by one point only in the area of Adjustment to Occupation.

Although the above achievements seemed insignificant, it is to be noted that for a severely retarded person only minuscule increments in skills could be expected specially when the person approached his/her potential. In this particular case, the subject covered most of the skills placed near the center of the social diagram which were most important for making severely mentally handicapped people more acceptable and less dependent. This is not to say that the program did not warrant any review or revamping. Such reexamination was imperative, and should be an ongoing process in program planning. In this instance, it appears that parent counseling could be useful to persuade the

subject's mother to be less protective, and thus to allow her ward to gain in self-confidence in daily living activities.

Conclusions

As pointed out by Sarason and Doris (1979, p. 4), "sensitivity to the social context reflects a transactional approach and is in marked contrast to much of today's separatism between diagnosis and program planning." The programs for the two subjects at the activity center, discussed in this paper, showed some concern for the above point of view, and attempted to integrate the diagnostic, program planning, and evaluative services into an ongoing process. The program efforts were, however, limited, inasmuch as the activities of the subjects in the other community agency and at home where these subjects spent most of their time could not be properly coordinated and monitored. This lack of an holistic approach to program development affected the process of normalization, which was so vital for mentally handicapped persons for learning, practising, and consolidating the skills of living.

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FIGURE 1

Name Subject A Age 21

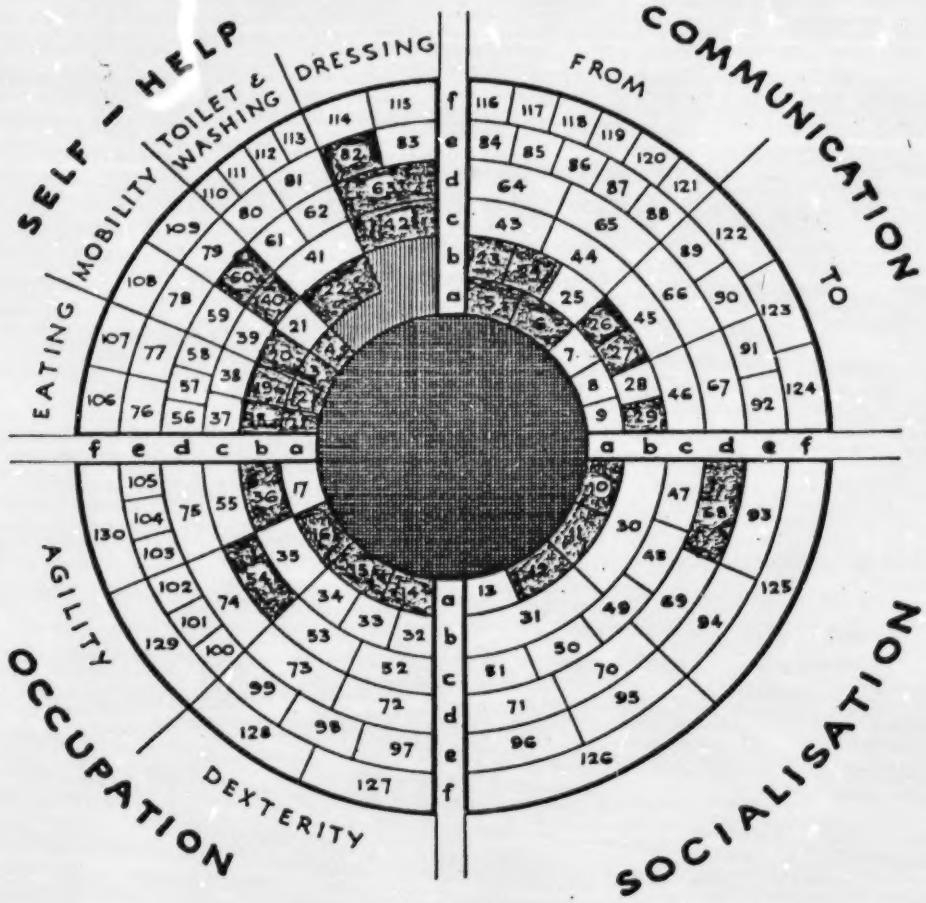

FIGURE 2

Name Subject A Age 22

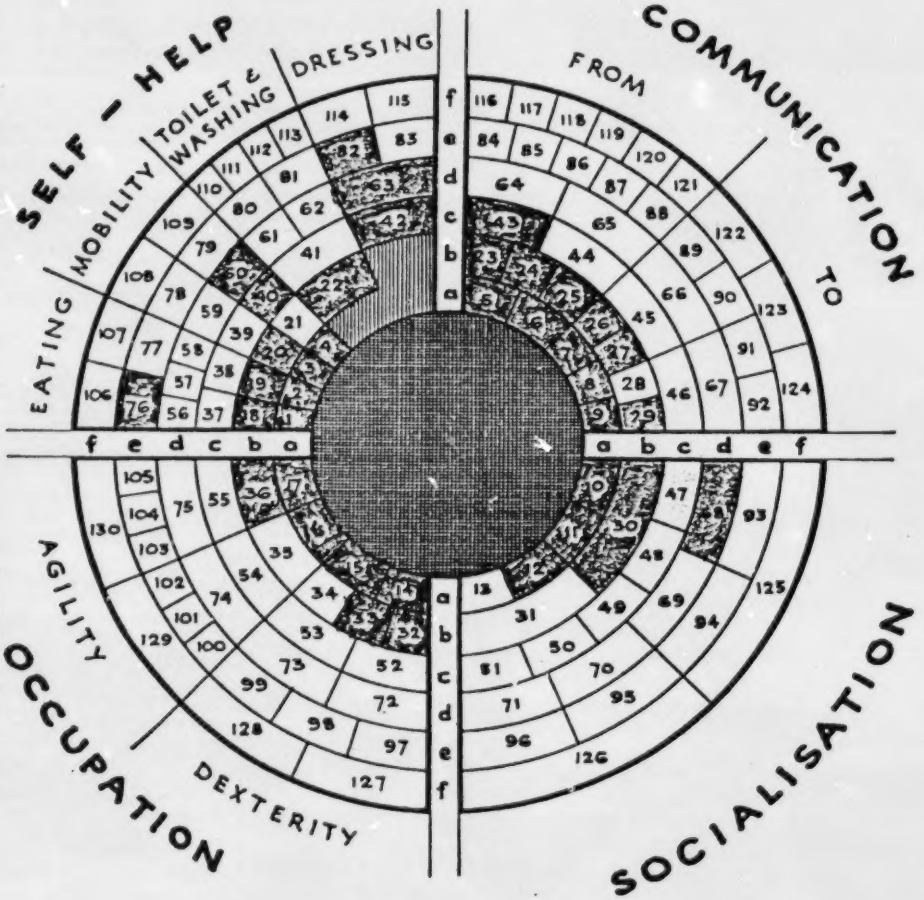

FIGURE 3

Subject A

Achievement of Skills in Social Development

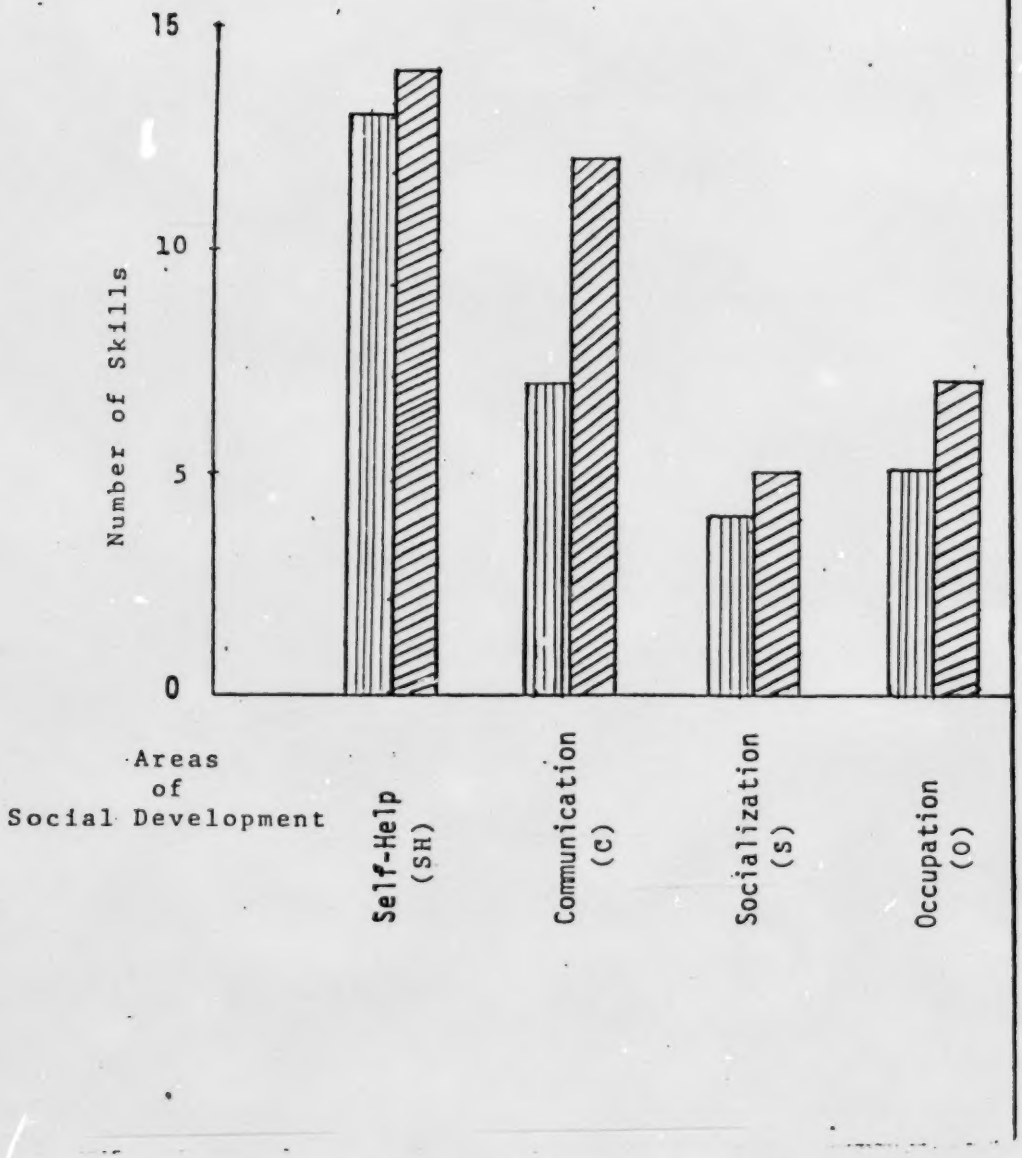

TABLE 1

Subject A

Social Competence Index (SCI)

SCI	At Age 21	At Age 22
Self-Help (SH)	41% (3.13 X 13)	44% (3.13 X 14)
Communication (C)	39% (5.55 X 7)	67% (5.55 X 12)
Socialization (S)	33% (8.33 X 4)	42% (8.33 X 5)
Occupation (O)	24% (4.76 X 5)	33% (4.76 X 7)
General	35% (1.22 X 29)	46% (1.22 X 38)

Note. SCI is obtained by multiplying the skill values derived from the Progress Evaluation Index (PEI) by the number of skills acquired.

FIGURE 4

Name..... Subject B ..... Age 24

SOCIAL ASSESSMENT

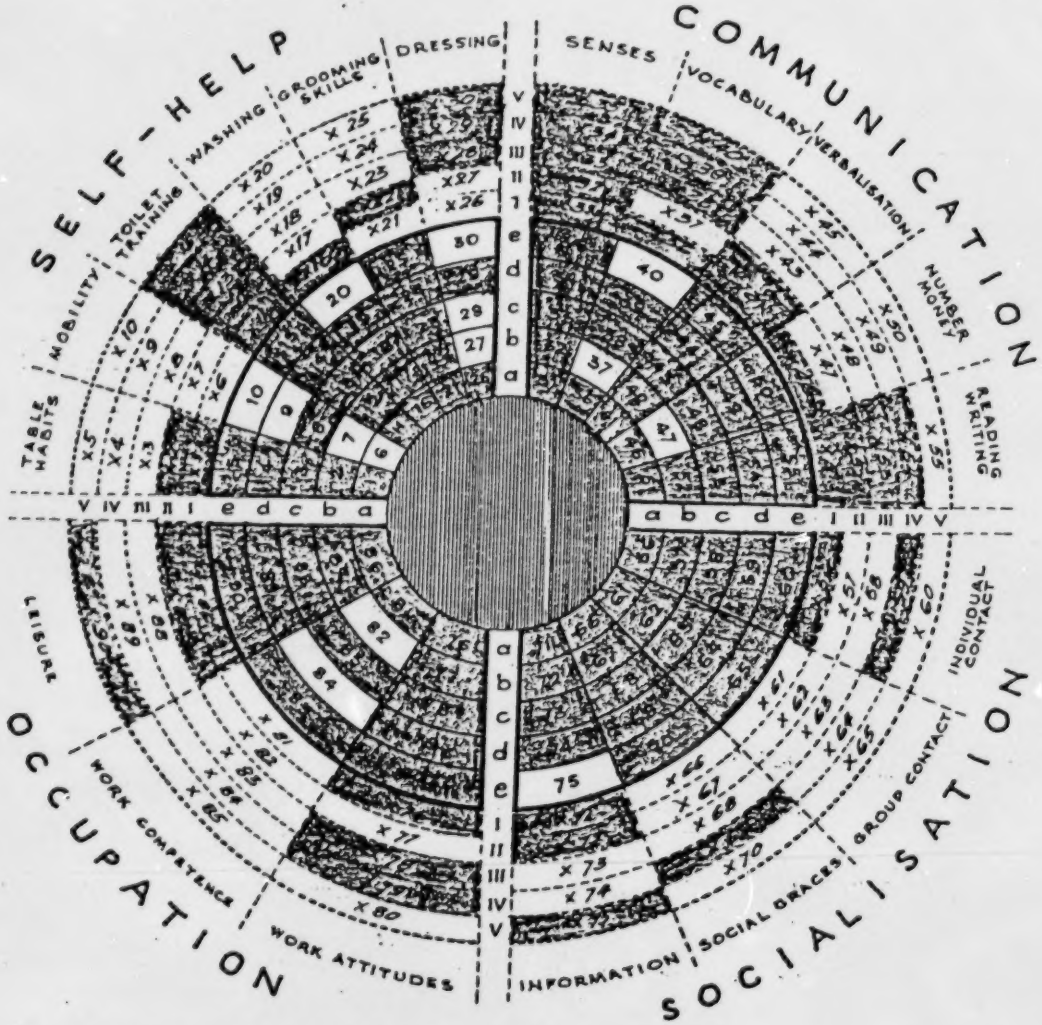

FIGURE 5

Subject B Age 24

PERSONAL ASSESSMENT

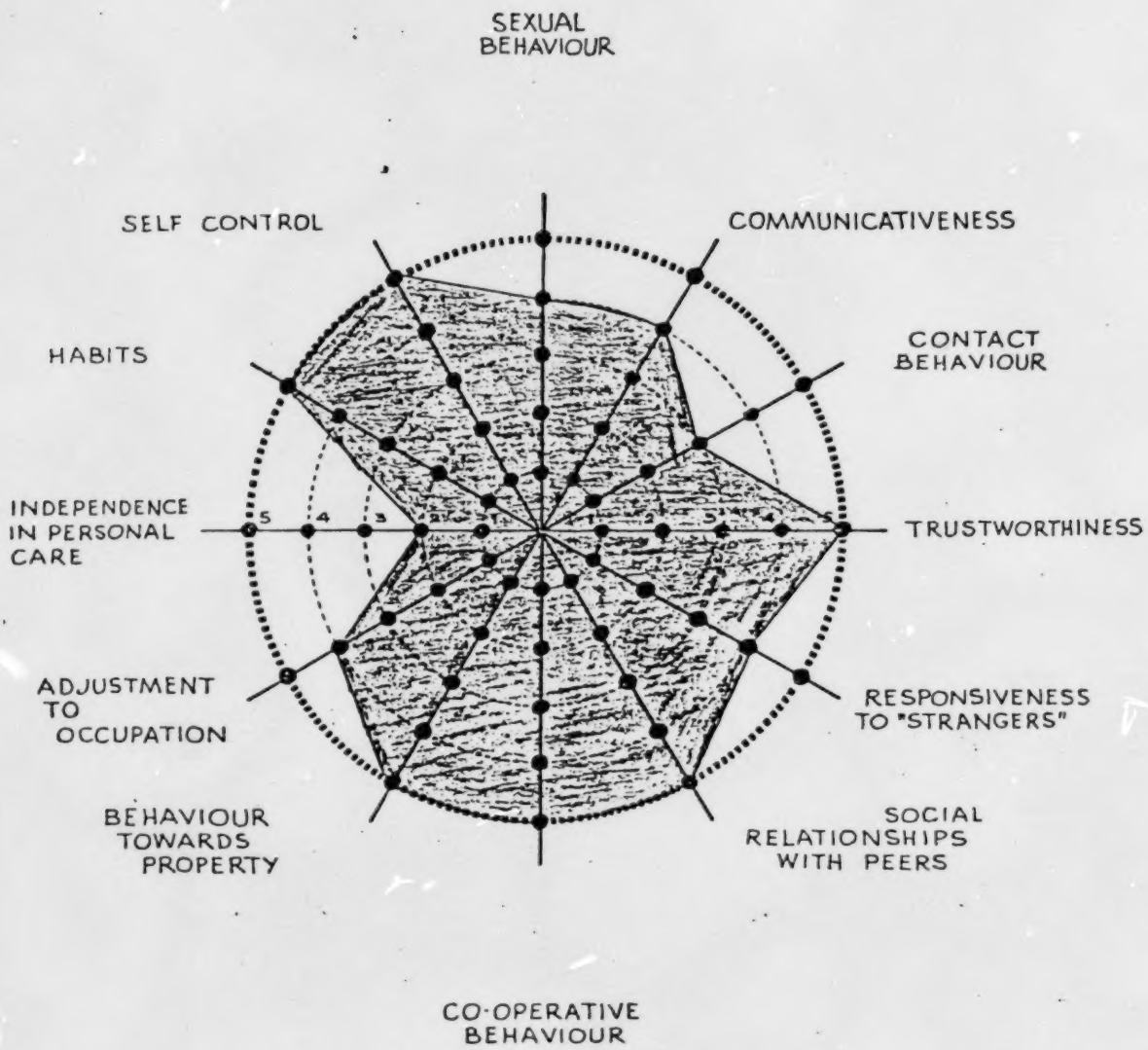

FIGURE 6

Name Subject B Age 25

SOCIAL ASSESSMENT

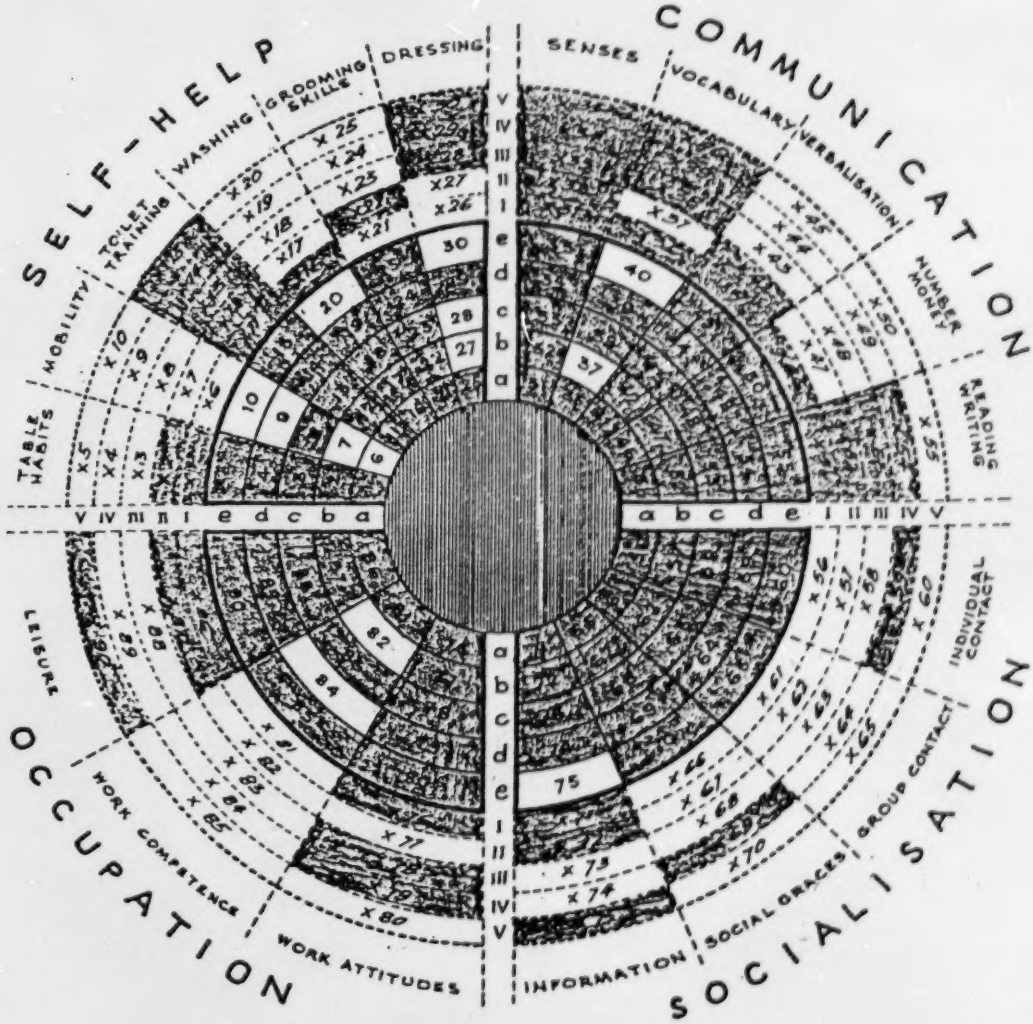

FIGURE 7

Subject B Age 25

PERSONAL ASSESSMENT